End of
life care

“Supporting Me”

A guide for Personal Assistants employed by or for someone with end of life care needs

Contents

1. Introduction

You have been employed as my Personal Assistant to support me so that I can live my life at home as I choose.

I may employ you through my Direct Payment that I manage myself, or people close to me may employ you on my behalf through my individual / personal budget.

Please remember that this is a working relationship and I want you to respect the professional boundaries and our roles in this working relationship.

About this Booklet and How to use it

This Guide is to help you understand how you can meet my needs and preferences as I come to the end of my life.

This Guide offers you information about end of life care and how you can offer me the support that I require.

This Guide will help you support me, however it may not include all of my wishes so please do discuss with me any aspects that you are unclear about and offer me the opportunity to give you more information about my personal preferences and needs.

You will find additional information at the back of this booklet that signposts you to other areas of support and information. The next page will highlight some of my key contacts to help you

My Key Contacts

My next of kin is: .....

Their contact details.....

My next contact is.....

Their contact details.....

My GP is .....

GP surgery is .....

My Care Manager is.....

Their contact details.....

My Community Nurse is .....

Other Community support .....
I may have

Their contact details.....

Why is this Booklet Important?

End of life care is different for everyone – just like any other aspect of my care - so please take time to make sure you know about me, what I want and how to support me. Talking with me and listening to me about my individual needs and wishes can make all the difference to my support. A lack of conversation may mean that my wishes and preferences get ignored.

Some of this Guide will look at my care and support needs and will include both practical and emotional aspects of my care; we may both find this difficult at times but ignoring things will not mean they go away, instead it may mean my wishes, preferences and needs are not met.

Some of the information in this Guide may not apply to me so please check with me or others who also support me.

2 End of Life Care and Support

One thing is sure as we all live our life – we will also come to the end of our life. I have enjoyed my life and now I want your support to continue this enjoyment.

This Guide is here to help you and me plan for my end of life care, it is all about how you provide me with good support so that I can continue my life with dignity and respect, with my wishes met where possible and my life celebrated.

Getting to know me – my health and well being

It's really important that you get to know me and about my health. Please take time to find out what I like, need and want.

There may be times when I can't tell you so please ask other people who are supporting me. There is a key contact list of people on page 5.

There will also be times when you must talk and liaise with other professionals who are also supporting me. Please make sure that you follow their advice and guidance.

My health and well being may change so please make sure that you talk to me about any changes and when necessary that you talk to the other professionals, my family and carers about any changes.

My views and thoughts about dying and my death

I may not want to talk to you about dying, if this is the case please respect this.

On the other hand I may want to talk about dying and about my arrangements and support. I may want to plan arrangements, I may just want to talk - remember it is ok to talk about dying!

I may have specific wishes or concerns and if we don't talk about this then my wishes may be ignored or go unfulfilled.

I may talk to you about my care and support, my plans, or just my thoughts and I may need you to help me talk to other professionals, my family and carers about what I want when I die.

It is important that you listen to me as well as talk to me and talk to other people who are part of my care and support.

If you are finding any part of my care and support difficult at any time you must let me know and between us we can decide on who are the best people to involve.

Showing me respect and dignity

It is important that you show everyone around me respect and ensure I have dignity in all my care and support.

Please be mindful of the language you use – some of the terms used for death and dying are not very respectful to me.

Remember I have made choices about my death and about my care and support when dying – please make sure you respect these and support me to fulfil these wishes.

If you are helping me with any aspect of my personal care please do this with respect and offer me privacy and dignity throughout.

It is also important that you treat my family, friends and other professionals with respect. Please do not talk about me to other people unless it relates to my care and support and they are people involved in my care.

Please respect my decisions and my culture, I may have spiritual beliefs that I also need you to support, please do not impose your choices, opinions or beliefs on me or on anyone else who is supporting me.

Please respect how I am feeling, I may feel happy or sad, I may feel angry or scared – please think about how you respond and how you support me.

3 Supporting me to live and die well

It is important to me that you support me to live my life – not just plan for my death. I may still have lots of things I want to see and do and I may need your support to do those things.

I still have a great life and I want to live it.

What is important to me and what I would like you to know

Choices and Decisions I may want to be involved in

Just because I am nearing the end of my life it does not mean I cannot make my choices and my own decisions.

Some choices and decisions I may make with other people, there may be some things I talk to you about and you may need to represent my choices and decisions to other people. Some of this may be about my treatment, and where possible, I want to be involved in as many decisions that I can. I may want to make a plan that shows my decisions and choices, I may ask you to help me with this. If a time comes when I can no longer make my decisions or be involved in them please make sure you talk to other people about the choices and decisions I made.

Please make sure you look at the additional information on Advance Care Planning and Mental Capacity Act in the information section at the end of this guide.

What is important to me and how you can support me

It is important that you know how to support me and what I like and dislike.

I have things I like to do, I may have places I like to go and people I like to see. I also have things that may annoy me, or make me miserable or simply things I do not want to do. Please make sure that you know as much about my daily life and routine as possible so that I can continue living my life.

Please focus on what I can do and what I want to do rather than what I cannot do or my illness.

My Advance Care Plan – Planning ahead

As well as living my life today I may want to plan for the future, particularly aspects of my later care and support. I may want to plan ahead and make arrangements and decisions in advance of my care and support. It will give me the opportunity to think about, talk about, and write down my preferences for my future care and support.

Who should get involved?
I may want to do this with my family, friends, with other professionals or with you.

It is always best to involve other professionals as some of these decisions and choices will affect the care they give me.

What might I include in my Advance Care Plan?
There may be many things that I want to cover, some may be about my care and support but some things may be about practical aspects such as my funeral arrangements and who I would like to be with me as I near the end of my life.

I may want to include where and how I would like to be cared for, things I want to happen and things I do not want to happen.

Please let me make my decisions about my Advance Care Plan and respect my wishes and preferences I include where ever possible.

4 I did this and so much more – a celebration of my life.

This booklet may be all about my support as I near the end of my life but please remember I also have a life to live and a life to celebrate.

I may simply want to take time to reflect or share some of my major life events with others around me so that we can all celebrate my life and my achievements. I may have things I still want to do and places I want to go and I may need your support to achieve these things.

My memories

My memories are my history and they will also be my family, carers and friends history.

If I decide I want to record my memories I may ask you to help me.

I might want to write them down, make a scrap book or photo album, make a memory box for family or friends, or write down my family tree for my family. It can be an important part of passing on and sharing treasured memories and occasions.

I may need you to support me and to help me, remember this is about celebrating my life and sharing my life with others around me.

I may want to put together some personal thoughts and memories for people close to me, such as:

- This is my favourite recipe
- This is a book you should really read
- Thank you for this memory I treasure it
- Watch this film – it was my favourite
- Do you remember this happening – it was so funny!

I may decide there are still places I want to visit, things I want to do so please make sure you help me achieve these things.

How I would like to be remembered.

As people come to the end their life other people often remember the last few days and months of someone's life, but I have lived my life, I have shared my time, my aspirations and thoughts with many; I have many strengths and abilities and I would like to be remembered by those around me in ways that celebrate my life and help them to live their life.

One of the things that I may ask you to support me with is asking people to help me put together a memory collection of how they will remember me. This may be written down, I may decide to record this or collect pictures. Either way I ask that you are sensitive to everyone around you, to people's feelings and anxiety and that you support me and others to remember me and my life.

5 People who are supporting me with my Care

It is most likely that other people are supporting me with my care. This could be my family, carers or friends as well as other health professionals and social care professionals.

There may be a range of other health professionals including my GP and Community nurses. I may receive support from specialist nurse teams, from hospital teams or a hospice. You must work closely with all of the health and social care professionals, this is vital to me receiving good care and support. You will need to liaise with them and listen to their guidance and direction, and they will also want to seek your advice and support.

There may be times when I have to go into hospital or I am supported at home by family, carers, friends or other professionals, please make sure you work alongside them.

I may also want to maintain contact with my spiritual support and places of worship I visit. Please respect this and offer me the appropriate agreed support.

Important people in my life – my family and friends

I may have a partner, spouse or children living with me and this is their home too. If this is the case please be mindful that as I near the end of life people around me may also need support. They may have or want a significant role in supporting me and this will be important to both of us so please respect that and offer them support as well.

I may have people who I want to visit or people who I enjoy visiting me, there may be times when I do not want to see anyone on that day! That is my choice and please respect that, please also be supportive of the person you are explaining this to.

I may want to talk to you about who is with me at the very end of my life, this may be family, carers and or friends, please make sure that you support these people as they are important to me.

My pets and animals

If I have any pets or animals please understand and respect that these will be just as important to me. I may worry about them, particularly what and how they will be looked after as I near the very end of my life. I may want to include these arrangements in my Advance Care Plan and talk to other people about their ongoing care and support. If I am worried about my pets and animals this will not help my ongoing care and support so please help me plan for their future needs as well as mine.

Other professionals you must know about

As I near the end of my life there are bound to be other Professionals who are supporting my care and well being, it is important that you link with all of these Professionals and work together for my best interests.

My G.P is most likely to be involved and part of the surgery support may be visits from the Community Nurse or a specialised nurse offering end of life care and support.

As part of my agreed needs I may have contact with a local hospice, a palliative care nurse or Macmillan nurses; all of the Professionals will be working to support my preferences and needs and for this reason I ask that you all work together so that this can be achieved.

6 How to support me when I become unwell

It is possible that I will become unwell when you are supporting me. Talk to me about how I am feeling and contact any of the other Professionals who are supporting me. If you are worried or do not know what to do talk to people who are important to me as they will know me well. If I become unwell very quickly and you are concerned then contact either my G.P or the emergency services.

It is important that we agree what you must do in such situations as there may be other people who I want you to contact or who I don't want you to contact. It is also important that we agree what is best with other Professionals.

What I want and do not want to happen

If I have completed an Advance Care Plan this should indicate certain aspects of my care and support that I want and do not want – please make sure that other people who are supporting me know all about this.

This may include specific wishes about where I want to die, what I want to happen around me, who I want to be there, as well as things I do not want to happen.

I may want to talk about and plan where I want to be at the end of my life, aspects of my care and support that I want or do not want, my funeral arrangements, the care of others who are important to me. You are a significant person in my care and support and these may be aspects of my support that I have talked to you about – hopefully we will have written them down.

Please make sure that you represent my ‘wants’ and ‘do not wants’ as this is my end of life and not anyone else’s!

My arrangements for my end of life

It may seem strange to people around me if I want to plan my end of life care arrangements. We spend a lot of time planning for someone to come into this life but often not a lot of time to leave this life. Please support me if I want to make my plans and my practical arrangements. I may do this with you or with family, carers and friends – we may all find this difficult and I ask that you are sensitive and supportive throughout.

My Funeral Plan

There may be practical things that I want to do and plan, such as my funeral. I may want to plan where I am buried, or cremated, the service, songs I want, and or any funeral directors instructions.

If I have not already done so I may want to make a Will.

I may want to agree all of my financial arrangements as well as anything else I consider important.

If any of these matters are important to me I may need you to support me so that I can talk to the necessary people, write it down if this is required and know that my needs, plans and wishes can be followed through.

Looking after other people who are affected by my end of life

My end of life may seem frightening and daunting to me, to you, and to other people who support me. We may all need additional support at some time. This may be talking to each other, talking to other Professionals, involving support agencies.

Different people can be affected in different ways, some people may be very emotional, angry, quiet or their behaviour may change. It is important that we acknowledge this and take time out from practical things to offer support where we can.

Some people are able to work through this on their own, others may need professional support and you will find more information on support agencies and organisations in section 7.

Remember you are important to me and if you feel you need additional support please do not hesitate to either talk to me or seek support from other appropriate people.

What to do if you are worried about me

There may be times when I become ill or I need additional support – please talk to me about your worries. Try not to make any decisions without me.

If you are worried about my health please contact the necessary health professionals and or my family and friends, it is best if we can agree what you might do in advance of any changes for me.

Remember we are all different, but it is important to act on any concerns. If it is possible talk to me about your concerns, tell me why you are worried and if possible we can agree what is best for me.

If I have written down or talked to you about what I may want please try and respect my wishes.

7 Useful Information

There is lots of information, support and guidance on supporting someone with their end of life care. You will need to think what additional support or information you require, remember this will help you support me and develop the skills and knowledge that you require to support me and anyone else.

I am your employer so it is important that you talk to me about this as I want to make sure you get the right support for your own skill development

You may find it useful to talk to other professional who may be able to direct you to some additional learning and support.

The website information on the next page may also help you.

Website and Resource Information

Skills for Care

Skills for Care have produced a Resource and Learning Opportunity Guide for End of Life Care which gives information on a whole range of learning and development resources. There are over 12 pages of potential resources and guides that you could access, many of these resources are free to the user. To receive this resource please contact Karen.stevens@skillsforcare.org.uk or telephone 07969749451.

The national Skills for Care website page will also offer you information on end of life development resources.

Go to www.skillsforcare.org.uk

Dying Matters

Dying Matters is a website with lots of support, guidance and resources to support users and carers with end of life care needs

Go to www.dyingmatters.org

The National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella organisation for all those who are involved in providing, commissioning, and using palliative care and hospice services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life-threatening and life-limiting conditions.

NCPC also run a project called 'small is beautiful' which explores the small things that make a big difference in end of life care. This publication is free

http://www.ncpc.org.uk/publications/index.html

NCPC have also produced a guide for professionals to support them in talking about end of life wishes with people affected by respiratory conditions. It's called 'Difficult conversations' Follow the same link as above to access.

To access website follow http://www.ncpc.org.uk/

Advance Care Planning

Advance care planning (ACP) is a core component of the EoLC Programme.

Guidance for health and social care professionals with regard to the implementation of an advance care plan has been published and is available on the website www.endoflifecare.nhs.uk.

ACP is a process of discussion between an individual and his/her care providers. If the person wishes, his/her family and friends may be included in the discussion. With the person's agreement, this discussion is documented, regularly reviewed and communicated to key persons involved in the person's care. Guidance can and should be sort to enable staff to fully understand and implement ACP.

Both sets of Guidance are very easy to read.

Guidance is available in Planning for your future Care – A Guide

Accessed via www.endoflifecareforadults.nhs.uk

Mental Capacity Act and Advance Care Planning

Advance care planning (ACP) is a voluntary process of discussion about future care between an individual and their care providers. If you have mental capacity, you are able to make decisions for yourself.

The Mental Capacity Act applies to situations where you may be unable to make a particular decision at a particular time, to the extent that you cannot:

- Understand information given to you.
- Retain that information long enough to be able to make a decision.
- Weigh up the information available to make a decision.
- Communicate your decision.

The Mental Capacity Act promotes best practice in supporting people who may lack mental capacity. The Mental Capacity Act sets out in law what happens when people are unable to make decisions, i.e. when they lack capacity to make a particular decision.

There are five key rules or principles that have to be followed by anyone who is supporting or working with a person who may lack capacity:

1. All adults have the right to make decisions for themselves unless it is shown that they are unable to make it. This means that people must not assume that you cannot make a decision for yourself just because you have a particular medical condition or disability, or because of your age or appearance.
2. People should be supported as much as possible to make their own decision before anyone concludes that they cannot make their own decision.
3. People are allowed to make a decision that may seem to other people to be an unwise or strange decision and a person should not be treated as unable to make a decision because of this.
4. If a person lacks capacity any decisions or actions taken on their behalf must be taken in their best interests
5. The final principle of the Act is to make sure

that people who lack capacity are not restricted unnecessarily. So the person making the decision or taking the action must consider whether it is possible to decide or act in a way that would interfere less with the freedoms and rights of the person who lacks capacity.

You can find additional information on the Mental Capacity Act at www.legislation.gov.uk or www.nhs.uk or www.publicguardian.gov.uk

National End of Life Care Programme

The National End of Life Care Programme works with health and social care services across all sectors in England to improve end of life care for adults by implementing the Department of Health's End of Life Care Strategy.

The website is designed to support health and social care staff working, in any capacity, with people nearing the end of life.

On the Home page you will see a box that takes you to Education and training. Click on *End of Life Care for All – e learning,* click on *Accessing e-ELCA,* scroll down to *Administrative & clerical staff & volunteers*

Visit www.EndOfLifeCareForAll.com where a number of relevant e-learning sessions are freely available without the need for registration.
www.endoflifecareforadults.nhs.uk

Macmillan Learn Zone

Takes less than 5 minutes to create an account. Once created you can log in and access information for Health and Social care Professional:

- News and updates
- e programmes and videos
- *We Learn* provides a gateway to an extensive range of generic e-learning programmes and resources, on a variety of subjects such as communication, software and management
- Toolkits and Packs
- Conference and online events
- Macmillan Information Resources

And much more!

Macmillan Learn Zone www.learnzone.macmillan.org.uk

Local Resources

Each area of the country will have local NHS services, palliative care services and additional end of life care support for you. Talk to the GP or other health professionals you are in contact with and find out what local support you can access.

Insert details:

This personal assistant 'Supporting Me' Booklet has been produced by Management Orient Ltd in February 2011, commissioned by Surrey Sub Group, Skills for Care South East. Other 'Supporting Me' titles are available from Skills for Care South East, please contact:

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Marianne Davis on behalf of Management Orient would like to say thank you to stakeholders and service users in the region who offered support and consultation to this guide, particularly to

Lucy Sutton Southcentral NHS, Joanne Black at NCPC, Sarah Ivey at Surrey PCT, and Rosemary Humphries at Macmillan.

Photos were supplied by Skills for Care